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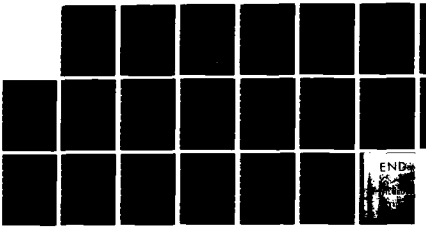

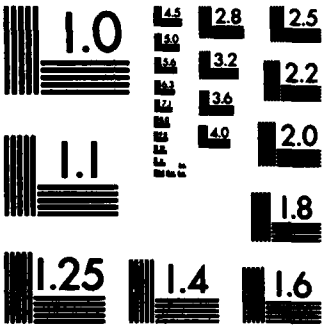

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HAIR LOSS MEASUREMENT TOOL DEVELOPMENT

A Manuscript of a Journal Article

Presented to the

College of Nursing

Brigham Young University

In Partial Fulfillment

of the Requirements for the Degree

Master of Science

by

Brenda S. Mueggenborg

August 1983

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HAIR LOSS MEASUREMENT TOOL DEVELOPMENT

Brenda S. Mueggenborg

College of Nursing

M.S. Degree, August 1983

ABSTRACT

Hair loss from cancer chemotherapy has received considerable attention in recent years in the field of cancer care because of the emotional and social distress it can cause patients. Many investigators have attempted to decrease hair loss by means of scalp tourniquets and hypothermia. A difficulty associated with interpreting the results of these studies has been the lack of a valid and reliable means of measuring hair loss. This study was designed to develop an instrument for measuring hair loss that is both valid and reliable. Tool development and revision are described. The tool was used to assess the hair loss of nine patients. Ratings were made by the patient and a single examiner initially. Photographs were also taken of the patients for use by other raters. Two sets of nurses used the hair preservation measurement tool to rate the patient photographs on two occasions each. Mean interrater agreement ranged from 72-76% in reliability tests of the tool. Mean intrarater agreement was 74% in tests for reliability. Validity tests are also described.

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HAIR LOSS MEASUREMENT TOOL DEVELOPMENT

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Hair loss from cancer chemotherapy has received considerable attention in recent years in the field of cancer care because of the emotional and social distress it can cause patients. Many investigators have attempted to decrease hair loss by means of scalp tourniquets and hypothermia. A difficulty associated with interpreting the results of these studies has been the lack of a valid and reliable means of measuring hair loss. This study was designed to develop an instrument for measuring hair loss that is both valid and reliable. Tool development and revision are described. The tool was used to assess the hair loss of nine patients. Ratings were made by the patient and a single examiner initially. Photographs were also taken of the patients for use by other raters. Two sets of nurses used the hair preservation measurement tool to rate the patient photographs on two occasions each. Mean interrater agreement ranged from 72-76% in reliability tests of the tool. Mean intrarater agreement was 74% in tests for reliability. Validity tests are also described.

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This manuscript of a journal article, by Brenda S. Mueggenborg, is accepted in its present form by the College of Nursing of Brigham Young University as satisfying the thesis requirement for the degree of Master of Science.

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June 14, 1983
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HAIR LOSS MEASUREMENT TOOL DEVELOPMENT

Hair loss and means of preventing it have received considerable attention in recent years in the field of cancer care. Hair loss is associated with a number of cancer chemotherapy agents and is frequently emotionally distressing to patients (1-5). Because of this distress, a number of studies have evaluated methods of preventing hair loss. One difficulty associated with these studies has been the lack of a valid and reliable means of measuring hair loss. Because of this lack, it has been difficult to assess the results of these studies. Each study has tended to use a different assessment method and it has been difficult to compare the various studies. Thus, the purpose of this study was to develop a valid and reliable instrument for the measurement of hair loss.

Cancer Chemotherapy and Alopecia

Certain cancer chemotherapy agents are more likely to cause alopecia than others. Drugs most commonly causing alopecia include cyclophosphamide, doxorubicin, and vincristine. Hair loss is moderately common with actinomycin-D. bleomycin, daunorubicin, and methotrexate. Alopecia is less common with 5-fluorouracil, hydroxyurea, mitomycin-C, and flouridine (2,6).

Hair loss is generally seen two to three weeks after chemotherapy is begun. The pattern and amount of hair loss varies

with the patient and the particular drug used. Some agents cause general thinning of the hair while others tend to result in severe and near total hair loss. Hair is generally lost over several days. It is more noticeable during activities such as washing or combing the hair, but hair may also be found in clumps or scattered on the pillow. Losses may occur over the entire scalp or in patches or bands (7-9). Men and women are equally affected (10). Hair loss is more evident in scalp hair. Loss of eyebrows, body hair, pubic and axillary hair is not often seen (11).

Regardless of the drug, alopecia is rarely permanent. Once the drug is discontinued, hair begins to regrow. Hair regrowth is sometimes seen while the patient is still receiving the cancer chemotherapy agent. However, the new hair which generally comes back two to three months after treatment may differ in shade, texture, or consistency (7,12).

Scalp Tourniquets and Hypothermia

Two methods have been widely studied for preventing chemotherapy-induced hair loss. These are the use of scalp tourniquets and scalp hypothermia. Scalp tourniquets are pressure cuffs placed around the entire scalp to occlude blood flow to the scalp during the time of high circulating concentrations of chemotherapy agents (13). During occlusion, other cells absorb or eliminate the drug.

Scalp hypothermia consists of using various methods for cooling the scalp such as applying ice packs to the scalp or blowing cool air across the scalp (4,15). Several rationales have been

proposed for the effectiveness of hypothermia: scalp hypothermia causes vasoconstriction which reduces the amount of the drug reaching the hair follicles; cellular uptake is decreased because drugs like doxorubicin require temperature-dependent metabolic processes for cellular uptake (14); finally, that the decreased temperature lowers the hair follicle metabolism resulting in reduction of the action of the drug (16).

Regardless of the rationale for use, both preventive methods have reported varying degrees of success. While the techniques used by the various investigators have almost certainly played a major role in the variability of the reported results, it is possible that the variability in assessing hair loss may also be important. These studies have used a great variety of assessment methods. Thus, their results are difficult to compare.

Hair Loss Measurement

A number of reports mention using either scalp tourniquets or hypothermia, but their methods for assessing hair loss are not described (17-22). These reports have been largely anecdotal or descriptive and have simply stated that either alopecia was prevented or reduced.

Another group of studies evaluated the results of hair loss preventive measures by rating patients according to categories. One set of categories used was total, severe, slight, and nil hair loss (15). However, these terms were not defined. Other investigators have used similar categories or have simply categorized patients into

no or minimal hair loss or extensive alopecia (13,23,24). Again, these categories or groups were not defined.

One popular method for defining or quantifying hair loss has been to describe hair loss in relation to when the patient finds it necessary to wear a wig. One example of this type of rating scale used four descriptive categories: (1) no significant hair loss; (2) minor hair loss remaining socially acceptable and not requiring a wig; (3) severe hair loss requiring a wig; and (4) total alopecia (25,26). Another study similarly categorized hair loss as slight, moderate, severe, or complete and related this loss to the need to wear a wig (27). None of these investigators reported any instrument testing for validity or reliability.

Another common method that has been used to quantify hair loss is the use of the percentage of hair loss. Percentages have been used in two basic ways. One study used a rating scale of protection from hair loss in which patients rated themselves and were also rated by nurses. The four categories used were excellent (0-25% hair loss), good (25-50% hair loss), moderate (50-75% hair loss), and poor (75-100% hair loss) (14). A study involving the use of Chemocap for protection from hair loss also used these four sets of percentage groupings (28). Neither study described whether reliability or validity of their hair loss rating scales was established.

Other studies have also used percentages to rate hair loss. In these studies, raters were asked to quantify hair loss on a continuum of 0-100%. Percentages of hair loss were then averaged between raters. Photographs were commonly used as a means of judging

patients (15,29,30). One investigator did test this hair loss measurement instrument for intrarater and interrater reliability, but did not state correlation values and intrarater measures were taken with a lapse of only three to four days (30).

These cited studies illustrate the problems that exist when interpreting results. No accepted instrument currently exists for measuring hair loss that has been tested for validity and reliability. This study was designed to develop an instrument that meets these requirements so that it may be used in future studies for better measurement of hair preservation and cross-study comparison.

Tool Development

In first developing the tool for hair loss measurement, hair loss patterns based on literature review and personal experience were taken into consideration. A difficulty associated with tool development was the observation that patients have different degrees of hair thickness. Because of this, some patients may lose more hair before hair loss becomes apparent and thus unacceptable. The important criterion identified was whether or not the hair loss was cosmetically acceptable. It was felt that the percentage or actual amount of hair loss would not accurately reflect the observable hair loss in a person with very thick hair compared to one with thin hair. Thus, a hair preservation measurement tool was developed.

Descriptions of hair loss and relation to the need for a wig or toupee were used as the basis for the tool as has been used by prior investigators (25,26). The tool was reviewed by master's level nurses who made suggestions to clarify wording and suggested adding a

one to four continuum scale to allow the rater some way of quantifying or visualizing the hair loss.

This resulted in the development of the original hair preservation measurement tool (see Figure 1). Hair loss or preservation was assessed by using an ordinal scale measurement. Ratings were made in categories of excellent, good, moderate, and poor. These categories were operationally defined on the tool. The tool was then used in two interrater reliability tests and tested for content validity.

Reliability Test #1 (Equivalence)

In order to initially test the hair preservation measurement tool for equivalence or interrater reliability, eleven patents were approached for participation. Five of these patients had or were currently receiving chemotherapy with epilating drugs and already had varying amounts of hair loss when approached. Six patients were beginning treatment with epilating drugs when they entered the study. These six patients used the scalp tourniquet in an effort to prevent alopecia and the hair loss tool was used to assess the effectiveness of the tourniquet. All patients had the study explained to them and consent forms signed.

The five patients who had received epilating drugs and had varying degrees of hair loss were given the rating form described above and were asked to rate their own hair loss. An observer then examined each patient's scalp and rated the hair loss using the same rating scales. Each patient's scalp was then photographed from four views: front, back, right side, and left side. These photographs

were taken for use in further instrument testing. In this group, there were three females and two males.

The six patients beginning treatment with epilating drugs were examined by the observer and four photographs were taken of each for later comparison. Two of the patients withdrew from the study, one out of choice, one because of death. After several courses of chemotherapy with doxorubicin, the four remaining patients were again asked to rate their hair loss. The observer also reexamined each patient and rated the hair loss using the hair preservation measurement tool. Four photographic views of each patient were then taken for use in further tests of the hair preservation measurement tool. In this group there were three females and one male.

The single observer and the nine patients were asked for suggestions on how to improve or change the measurement tool. No changes were thought necessary. In eight of the nine ratings, the observer and patients agreed. In only one case agreement was not reached. In this case, the patient rated herself as having only moderate hair preservation and the observer rated it as good hair preservation. It is significant that the patient did comment that she viewed her hair loss as much worse than her family and that they felt she did not need to wear the wig which she wore. Agreement was reached in 89% of the ratings. The rating form used in this reliability test is shown in Figure 1.

Reliability Test #2 (Equivalence)

In the second test for interrater reliability or equivalence of measures, nine health professionals working in the field of

oncology were asked to rate the same patients using the photographs taken earlier. As previously mentioned, five of the patients had photographs taken only after hair loss had occurred and four of the patients had photographs taken before and after epilating drug use. There were six females and three males in the patient sample.

The rating form shown in Figure 1 was used with this group of raters. Agreements ranged from 44% to 100% among the raters. The median and mode were 78% agreement; the mean percentage of agreement was 77%.

Validity Test #1 (Content)

The nine oncological health professionals were asked to critique the measurement tool after completing their ratings. All felt that the descriptions had components with which both the patient and health professional could identify. However, they all felt that the tool was too subjective and that they needed a more concrete basis for rating. All had difficulty with the term "socially acceptable"; they felt that more hair loss was socially acceptable in males than females and thus they had a tendency to rate the male patients higher or better on the scale. Two persons felt there should be more descriptive categories. Three of four professionals felt that the use of percentage categories would help alleviate the difficulty in rating male patients and make the tool more accurate. All felt that the one to four number continuum was not useful to them in rating the patients.

Tool Revision

Based on the critiques of the oncological health professionals, revisions were made in the hair preservation measurement tool. The tool was revised into the same four basic descriptive categories (see Figure 2). Phrases which caught the rater's attention and resulted in value judgments such as "socially acceptable" were removed. Descriptive titles for each category were removed from the front of the description so the rater would not be blocked by them and fail to read the full descriptions. Percentages were added to overcome the problem in rating male hair loss and to provide a more concrete dimension for rating. The tool now combined the two major criteria that have been used in past studies for rating hair loss or preservation. This revised tool was tested on three separate occasions for interrater reliability. Test-retest reliability or stability testing was done and further validity measures were computed.

Reliability Test #3 (Equivalence)

After the above tool revisions, a group of eighteen nurses was asked to rate the nine sets of photographs for hair preservation or loss using the descriptive categories. Figure 2 shows the rating form that was used in this reliability test and all remaining tests for reliability and validity. These eighteen nurses were registered nurses working on their baccalaureate degrees. Overall they had no special experience or additional educational background in oncology. The group consisted of seventeen females and one male.

Agreement ranged from 56-94% among the eighteen raters. The median agreement percentage was 72%; the mode was 67% agreement. The mean percentage of agreement was 76%. These values are quite similar to those obtained with the nine expert raters using the original hair preservation measurement tool.

Reliability Test #4 (Stability and Equivalence)

The hair preservation measurement instrument was then tested for stability or test-retest reliability. The group of nurses used for reliability test #3 was again asked to rate the same nine patient photographs using the revised hair preservation measurement tool shown in Figure 2. This retest took place three weeks after the initial ratings were performed. Fifteen of the original eighteen photograph raters participated. This group consisted of one male and fourteen female raters. The percentages of agreement were calculated for each of the fifteen raters' sets of scores. The range of the percentages of agreement was 55-100%. The median and mode of the percentages of intrarater agreement were 67%. The mean of the percentage of intrarater agreement was 74%.

Intrarater agreements were again calculated with this group of raters as an additional test for equivalence of measures. The range of the percentages of agreement among raters was 60-87%. The median of the percentages was 73% agreement and the mode was 80% agreement. The mean percentage of interrater agreement was 74%. This compares very closely with the percentages of agreement obtained in the prior test. Critique of the hair preservation measurement tool was then requested from these raters. This critique established that

the raters continued to have difficulty rating male patients and that they also had difficulty making a rating when there were no "before" photographs for comparison.

Validity Test #2

In determining validity, three major characteristics were considered: content validity, criterion-related validity, and construct validity. Criterion-related validity refers to the ability of the instrument to correlate with some other criterion. Since no well-established or proven method of measuring hair loss exists, this aspect of validity was not tested. Construct validity refers to whether or not the instrument is measuring what it is supposed to measure. The nine experts did judge that the important variables of hair loss were covered by the instrument and thus construct validation was supported. However, no formal testing of construct validity was done due to the lack of established attributes for comparison.

Content validity refers to the sampling adequacy of the content area being measured. In other words, have all of the important issues in an area been addressed and does the instrument contain a representative sampling of these areas. As cited earlier, issues in hair loss that have been identified as important are the cosmetic effect, the pattern of hair loss, and the total amount of hair loss. Four outpatient chemotherapy nurses, three inpatient oncology nurses, a master's level student in oncology nursing, and a professor in the master's level oncology nursing program were consulted in preparing the revised hair preservation measurement tool.

Reliability Test #5 (Equivalence)

It was hypothesized that the interrater agreement with use of the hair preservation measurement tool would be improved when used by nurses with a clinical background in oncology. Thus, six of the original nine expert raters were again asked to rate the nine sets of photographs using the revised hair preservation measurement tool. These new ratings were performed two months after the photograph ratings were done using the original measurement tool in order to avoid bias from recall of their previous ratings.

This group of expert raters was composed of a professor in the master's level oncology nursing program, a master's level student in the oncology nursing program, and four chemotherapy nurses working in the offices of medical oncologists. Agreements ranged from 50-100% among the six expert raters. The median and mode of the percentage of agreements was 67%. The mean percentage of agreements was 72%. Thus, the hypothesis was not supported. There is no improvement in the percentages of agreement between the expert raters and the nurses without an expanded oncology background. Mean percentage of interrater agreement for the group of nurses without an oncology background was 74-76%.

Since it was commonly voiced that it was more difficult to rate patients with no "before" photographs, the ratings of the two groups of patients were compared for reliability tests 3, 4, and 5. A comparison of the mean percentage of interrater agreement for these three reliability studies using the revised tool show a significant difference between the ratings for the patients with "before and

after" photographs and those with only "after" photographs. The mean percentage of agreement for the five patients with only "after" photographs was 69% while the mean percentage of agreement for the four patients with "before and after" photographs was 81%. Thus, a significant difference in interrater agreement does exist.

Conclusions and Recommendations

The results suggest that the hair preservation measurement tool can be useful to investigators. Overall, rater agreement on the amount of hair loss of the patients was greater than 70%. Table 1 summarizes the results of the reliability tests using the revised measurement tool. However, the measurement tool is a subjective measure of hair loss and thus has certain weaknesses over an objective measurement device.

A commonly voiced difficulty associated with the use of the hair preservation measurement tool was that male patients were more difficult to rate than female patients. This difficulty was felt to be due to the subjective judgment of the raters that hair loss in male patients was more cosmetically acceptable and thus not viewed as "abnormal" by the raters. It was also felt that male patients are not as likely to wear toupees when hair loss occurs. This observation concerning the wear of toupees does not concur with the investigator's personal experience. While not all male patients chose to wear toupees when they have significant hair loss, many do not find hair loss acceptable and will begin to wear a toupee. In fact, a 70-year-old man in this study did wear a toupee after he had significant hair loss even though he had thinning hair prior to the use of epilating

drug. While this problem was identified by the raters, it should be noted that the mean percentage of interrater agreement with the revised tool was 75% for the female patients (N = 6) and 72% for the male patients (N = 3). This difference is not significant. During future testing and use of the measurement tool, this difficulty with assessment of male patients should be further studied. It might also be interesting to see if a difference exists between male and female raters. Since only one male rater participated in this study, this difference could not be studied.

At this point, certain limitations of the study should be noted. One problem was the small number of patients that were enrolled in the study. The tool should be used with a larger number of patients in order to adequately assess the instrument. In addition, the number of raters involved in the study was small. More raters will be needed to refine the measurement tool. The reliability retest period of three weeks was short. It has been suggested that at least one to two months elapse for a long-term retest. Raters in this study also found it difficult to rate the photographs where no "before" photographs were available for comparison; since the subjects had varying thicknesses and amounts of hair prior to the use of epilating drugs, this was a valid criticism. Greater reliability was apparent in this study when the rater had a means of comparing the current amount of hair to the patient's original amount of hair prior to the use of epilating chemotherapy drugs.

A puzzling finding in the study was that the percentage of interrater agreement actually decreased among the expert raters when

the revised tool was used. In reliability test #2, the nine expert raters had a mean percentage of agreement of 77%. In reliability test #5, six of these expert raters were asked to rerate the photographs using the revised tool. In this test, the mean percentage of agreement was 72%. Thus, it might be debated whether or not the measurement tool was actually improved. Both of these rater samples are very small and it is difficult to assess the validity of these findings. Further study will need to clarify this issue.

Further work is indicated in refining the scale descriptions especially in the middle range of hair loss. Raters found that the scale was easily used when the hair preservation or loss was extreme -- either no hair loss or total alopecia. The biggest difficulty arose in rating patients that fell into the middle range. Rater errors were also found in the use of the measurement tool. A few raters tended towards a central tendency error and would not rate patients at the extreme -- either excellent or poor. The rater error of severity was also found; a few raters tended to underestimate the hair loss in all patients. Overall, it was noted that most photograph raters did not agree closely with the patient's perception of his/her hair loss. Since there was very close agreement between the single examiner and patients' ratings, the tool may be best suited for this use. However, further study should clarify this issue.

A serendipitous finding from this study was an observation made concerning the use of scalp tourniquets. Four of the patients in this study used a scalp tourniquet for the prevention of hair loss from doxorubicin. While these patients had varying degrees of

success with the tourniquet, all four patients did have excellent hair preservation at least in the scalp areas covered by the tourniquet. In fact, one patient retained only a band of hair around her scalp.

The hair preservation measurement tool should be useful to investigators interested in assessing hair loss and/or measuring the effectiveness of methods to prevent hair loss. However, there are limitations to the instrument as have been noted. Further study should clarify or rectify these problems. Another issue that might also be addressed in future tool development is whether the use of percentages alone in measuring hair loss is an improvement over the present tool. With tool refinement and improved interrater reliability, the hair loss measurement instrument may also be useful to Medicaid and health insurance firms in assessing cancer patients for wig reimbursement.

APPENDIX

HAIR PRESERVATION MEASUREMENT TOOL

Please place an X by the category that best describes the patient's hair loss or preservation:

_____ Excellent: No hair loss or minimal hair loss that is not significant or noticeable by others. The patient may notice a very slight increase in hair loss during hair combing or washing or may see no difference from normal. Is rated one on a hair loss scale of one to four (excellent to poor).

_____ Good: Minor hair loss that is noticeable to others as a slight thinning, but is socially acceptable in that it does not require the wearing of a wig, scarf, or toupee. The patient may notice an increased amount of hair loss from usual when washing or combing hair. Is rated a two on a hair loss scale of one to four.

_____ Moderate: More severe hair loss that is very noticeable to others as hair loss, and is not socially acceptable in that it requires the wearing of a wig, scarf, or toupee. The patient may notice large clumps of hair on pillow and during washing and combing of hair. Is rated three on a hair loss scale of one to four.

_____ Poor: Total or near total hair loss where only a few small patches or strands of hair remain. Is rated four on a hair loss scale of one to four.

Figure 1. Original Hair Preservation Measurement Tool Rating Form.

HAIR PRESERVATION MEASUREMENT TOOL

Please place an X by the category that best describes the patient's hair loss or preservation:

_____ No hair loss or minimal hair loss that is not significant or noticeable by others. The patient may notice a very slight increase in hair loss during hair combing or washing or may see no difference from normal. Hair loss is 0-25%. (Excellent)

_____ Minor hair loss that is noticeable to others as a slight thinning, but may not require the wearing of a wig, scarf, or toupee. The patient may notice an increased amount of hair loss from usual when washing or combing hair. Hair loss is 25-50%. (Good)

_____ More severe hair loss that is very noticeable to others as hair loss and may require the wearing of a wig, scarf, or toupee. The patient may notice large clumps of hair on pillow and during washing and combing of hair. Hair loss is 50-75%. (Moderate)

_____ Total or near total hair loss where only a few small patches or strands of hair remain. Hair loss is 75-100%. (Poor)

Figure 2. Revised Hair Preservation Measurement Tool Rating Form.

Table 1. Summary of Reliability Tests Using the Revised Hair Preservation Measurement Tool.

Reliability Test #	Number of Raters (N)	Background of Raters	Range of Percentage of Agreement	Median	Mode	Mean
3 (Equivalence)	N = 18	Nurses with no special oncology background	56-94%	72%	67%	76%
4 (Stability)	N = 15	Nurses with no special oncology background	55-100%	67%	67%	74%
4 (Equivalence)	N = 15	Nurses with no special oncology background	60-87%	73%	80%	74%
5 (Equivalence)	N = 6	Nurses with special oncology background	50-100%	67%	67%	72%

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